

# HIV Planning Steering Group Meeting Minutes

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**Date:** Thursday, November 21, 2019

**Time:** 10:00 a.m. to 3:00 p.m.

**Location:** Kent – DOH Office Room 309

**Community Co-Chair:** Jasmine Gruenstein

**Governmental Co-Chair:** Tom Jaenicke

**Members Present:** Judith Billings, Kathy Brown, Lauren Fanning, George Fine, Matt Golden, Warren Leyh, Melissa Roberts, Joseph Ready, Maria Benavides, Erick Seelbach, Lara Strick, Shauna Applin,

**Members Absent:** Adrian Aguilar-Perez, Scott Bertani, Shireesha Dhanireddy, Jsani Henry, Evelyn Manley-Rodriguez

**Community  
Members:**

Kaitlyn Simmons, Dennis Torres, Ryan O'Brien, Drew McCarthy, Eldridge , Michelle Bonelly- Vice, Stewart , Mark , Michelle Silvers, Jax Swimmer, Deirdre Burrow, Vanessa McMahan

**DOH Staff:** Beth Crutsinger-Perry, Tamara Jones, Vanessa Leja, Maggie Miller, Kelly Naismith, Carri Comer, Cher Levenson, Jennifer Reuer, Lydia Guy Ortiz, Emalie Huriaux, Chris Wukasch, Sarah Deutsch,

## **Welcome and Housekeeping**

*Agenda Review and Proposed Changes*

*Agenda with Action* – Motion to Approve: Judith      Seconded: Maria

- Debrief from HCA meeting: Moved to January. An email was sent with some notes for people to review and will discuss in January, but if there is time at the end can be covered. Carri suggestion to wait until January so that we can have a discussion and not just an update.
- Agenda Approved

*Minutes with Action* – Motion to July and September Approve: Joseph Seconded: Melissa  
Minutes Approved

## **Survey Report Back – Jasmine Gruenstein**

Survey results provided in meeting packet for today. There is an increase of participation from members.

## **Report Back from Newsletter**

Beth – the intent for the newsletter is to provide information that we can not always cover during HPSG meetings and have things that we want folks to know about. The intent is not for fluff, but things that we think are important. If the newsletter is not helpful then we can identify

other ways of to get information out. There is a limited scope to who this newsletter goes out to.

### **HPSG Report Outs – Vanessa Leja**

Lara – raise an issue that inpatient psych hospitals are not providing HIV medications. There have been a few patients for are involuntary commitments that are not providing meds for months at a time. Not sure if these are public or private in King County. Community based agency was asked to bring meds. Matt and Carri have asked for follow-up to help.

Lauren – Piggy back on the issue and has a client in Kitsap jail, their medical is inaccessible and meds are not being ordered and requiring parent to bring meds, changed meds and then not receiving. Since privatized this is an increasing problem and case managers are not able to reach in and clients are not able to reach out.

- Beth suggested reaching out to local health officer to see if they are able to help.
- Lara reminded the group that the jails could contact EIP to get meds. Beth mentioned that the jail does have to reach out to EIP.

### **DOH Brief Program Announcements**

Emalie – Partnering with Tacoma groups for the 3<sup>rd</sup> community event around Hep C. Will email information to the group.

### **OID Planning System Structure – Tom Jaenicke**

Slides provided in packet

### **OID Needs – Tom Jaenicke and Vanessa Leja**

Goals: Syndemic approach, equitable, reduce carbon footprint

A formal planning body, subject matter expertise groups, and conversations with wider community audiences.

### **Case Studies - Emalie Hurlaux**

Hep C – Examples of case studies come from field services staff. Names and details changed so not to breach confidentiality. Building a syndemic system of care

- Attached herewith, below
- Clinical workgroups for HPSG and Hep C free have some of the same participants and have some of the same challenges and would be more effective and have less meetings if we take a more streamlined way to have these conversations.

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### **Equity and Membership on HPSG – Lydia Guy Ortiz**

DOH Inequity and Equity Implications infographic provided. We can't have bodies that aren't representative of the epidemic. The body as is, is not representative of people of color especially in the black community. Looking at the applications there appears to be some implicit bias. Whatever we do with membership, it requires active intervention to be more equitable.

Equity vs Equality infographic shows the third step of removing barriers.

Equity considerations for HPSG membership slip – these are things to be considered for equity

### **Meeting Frequency and Remote Participation – Vanessa Leja**

Talked about this back in May. Meeting frequency was originally designed to only meet quarterly but changed when the work required meeting more frequently.

We would like members to discuss remote participation and do some cost benefit analysis. How can we more responsible to the earth, more cost effective, and decrease the number of meetings people have to attend.

Group Work:

HPSG Group Report Outs:

Syndemics –

- Overall impression in agreement that the syndemic approach is necessary
- Have concerns about how that functionally plays out
  - o The original intent was to be an integration of multiple bodies
  - o Does it increase the work by adding other areas and doesn't work with less meetings
  - o Concerns about how to insure equity and representation – increased need for rep and what size body is needed and how to get work done
  - o How does infrastructure and funding work at the ground level. Clinical organizations may be better to do integrated work but what about the community basis....how does it thread through the whole system and not be fractured
  - o What is the function of the body – advisory or planning? Add objectives and measurable outcomes so that we know what we are working for and what we are trying to obtain.
  - o Lots of opportunities to do smaller work groups but also lends to challenges and what the flow of work and the representation of those work groups
- Definition of planning vs advisory: planning would be given the current context what are we doing vs, DOH is doing X and how does the group advise?
- The body is struggling with are we planning or advising and feel like we are doing neither.

HPSG

- What is the actual overlap of those areas between HIV, HCV, DUH and defining that.

Equity and Membership –

- Identify barriers for membership: recruitment and application – be intentional and specific with reaching out to those outside of the same and usual networks. More formal
- Update application and outward facing description of HPSG. Is the application what we want it to be is it what we want to be.
- Public facing does the letter and description work – should it be simplified.
- The application step back and ask what you need to know and what you want to know when considering that person and how do we make it more accessible.
- Clearly defined message of OID purpose for the group in order to recruit those in an equitable way.
- How to make the meetings warmer, more casual and more inviting for new people.
- Easier to collaborate and get to know each other.
- More small group
- How do we sell the group to people to ensure that they want to join it.

#### Meeting and Frequency and remote participation –

- Would like to meet in person and face to face quarterly as opposed to remote
- Quarterly reduce the burden on DOH staff, reduce the cost, (depends on if the group gets bigger and come from farther)
- Have an emergency clause that online meetings, email, or conference call for emergent issues.
- 5 hour webinar would be too long
- Not opposed to meeting every other month, but quarterly does feel enough

#### Overall Discussion:

- Cost for HPSG, if we integrate with other groups the availability of resources and costs discussion changes.
- Cost consideration and back to the equity – the barriers of being part of this group. Most people are compensated by their jobs to be here. To be more effective is to put money aside to pay people to be here or look at it as a contracting or consulting who are informing and influencing the work.
- Quarterly sounds good and feels better for time, but there are concerns about shortening the meeting to get things up and running...is this successful should we meet more frequently as we start and then go to less.
- Beth – Context, which is still open to discussion. Yes, this is a lot and we are not exactly sure how to do it and have reached out within our division who has a lot of experience working with advisory bodies and how they work. This group has not been set up as consistently as maybe other advisory groups. There are parts of this process that need more time and the expectation to just flip the switch and it may take up to a year to come out of this process and feel that things are well thought through. This is an opportunity to get feedback as we think through this process.
- Historical trend and 30,000ft level – slow process in which DOH is devaluing this body and its decision making process. Given the history of HIV and involvement with the community...slowly being stripped away and there is less purpose...each time there is less clarity of purpose. Concern is that the next shift will remove that even more.
- Uncomfortable balance of looking at how HIV work integrates with other issues such as drug use, Hepatitis...how we get ahead.
- Prime time to look at our priorities and collectively address all these in a syndemic way but still not lose certain elements of HIV work.
- Part of the hope is that there is engagement of folks outside of DOH as we do our planning and creating an understanding of what this group will look like. Have an interactive process to figure that out. Create a clear and accessible idea of what we do to get people at the table who usually are not able to get to the table. Request for clear and open dialogue.
- We are all on the same page as understanding what the meaning of our purpose is here and that may dictate how often we need to meet or answer some of the other questions.
- The syndemic is going to be different in each area of the state and the approach. Would it be better to have more local groups that are able to meet and be supported by OIA and have representatives from those areas be part of HPSG.
- Missing AIDS Net and how that contributed.
- Things have changed dramatically since the governor's council and there was more action and recommendations that were taken and acted upon versus now. It was more of an activist group compared to what we are seeing now. Really need to define what we are and what authority we have when making recommendations. Or are we a body that is here just as advice and not planning and implementing.

- Discussion about membership and those who have been passed the time stipulated in the bylaws and how do we fill the gaps from some of those members leaving such as providers. How do these changes affect some of the newer formed groups...
- Clarifying conversation – 21 member body there are 10 members whose terms have expired but are currently still sitting. The bylaws so no more than 4 years total. There was a conversation of having people rotate off and concern that some of those folks are the doc group that are important and the conversation is to have them rotate off but still continue on the clinical group. DOH took a pause and have paused on that conversation and look more at the group and not individuals.
- In May we started the discussion of following the bylaws and looking at them we are discovering that there are a lot of things that we are not doing and need some of those folks who have that history here to help give some of that purpose for those who are new. Need to adhere to the bylaws we have or create new ones that align with where we need to go.
- As we have this conversation there are a lot of folks not in this room that need to be engaged because those voices are not sitting here and historically have not been seated here. Specifically communities of color.
- Participation on HPSG hasn't been outreached very well to people of color and the application needs to be simplified and not feeling like you're applying to college. Have to step back and identify what we want because people of color don't want to be that token representative.
- Being here are a representative of our communities and advocating for them. This should be a space for change.

### **Drug User Health Focus Group Presentation and Vulnerability Survey**

Presentation provided in packet

### **Legislative Package Update**

Community aspect: Lauren and Erick

- Ongoing calls that have community, DOH, and Leg representative that happens every two weeks. Interested participants please contact Lauren or Erick.
- Going forward with last year's bill as an agency request. It will start in rules and will be moved to the house.
- There is a technical amendment
- Conversation is what is the legislative strategy to get it passed? Erick and Scott are meeting with the staffers in the health care committees. Conversations with Kari Morris who is committed to working on the bill and has been doing HIV lobbying for a long time.
- No concerns about it being housed of the house and hopefully quickly.
- Questions about whether or not is is perceived as Laurie Jenkins, Cody will be the prime sponsor. Senate, Randell is the prime sponsor.
- Endorsed by the Board of Health, Senator Liase has asked for an impact review to look at the impact on health disparities with the bill.
- The Board of Health is also endorsing the legislation.
- Speaker doesn't usually sign in on legislation and is being removed from every bill that she was a prime sponsor last year.
- The Senate bill is being resurrected so it won't be heard first on the floor.

Provided the local public health officers, 4 documents; departments talking points, fact sheet, HIV then and now, overview of DIS in Washington State

Beth has two meetings on the hill tomorrow around this. Conversations with Columbia Legal Services and Washington Defender Services.

Health officers have been briefed several times. They talked about the importance of health officers reaching out to prosecutors about the bill.

There are some technical changes that need to be made and there may be other changes as things come up. This is going to be a short session so work has started to get information sheets out.

## **Closing**

Next Meeting: January 16, 2020

## Case Studies:

I'm going to present some examples of individuals with complex lives, who are experiencing multiple overlapping issues, and that we have been challenged to support through our existing system of care. These examples all come from our field services team. Any names I use are made up and in some cases I have changed minor details to ensure I do not breach any confidentiality. We highlight these examples to highlight the need OIA has identified to address our system of care from a more syndemic lens. In addition, I offer these examples to ground us in the idea that if we build a system of care that would serve these people then our system will be able to serve anyone impacted by the syndemics of HIV, STDs and HCV.

### Case Study #1: Cassandra

- Cassandra is a Latina woman in her 40s currently experiencing homelessness in a smaller urban city
- She injects drugs, mainly heroin, and is a survivor of sexual assault
- She was diagnosed with HIV in spring of last year at a substance use disorder treatment center
- She is also living with HCV, for which she has not received any care or treatment
- She was referred to a local clinic and urgent care for health care related needs, including related to her HIV diagnosis
- Since that time she has been a victim of sex trafficking and experienced violence
- A disease intervention specialist from DOH has been trying to locate her since her diagnosis, including through street outreach efforts.
- She was finally located in late summer and it took two months for the DIS to convince her to meet with him in person.
- This fall, Cassandra and the DIS agreed to meet at a local fast food restaurant on a weekday afternoon.
- When Cassandra showed up she was badly bruised and reported that she had been abused by other members of the encampment where she sleeps. In addition, she was covered with sores, consistent with being immunocompromised.
- The DIS offered to help her find shelter and get connected to medical care, so Cassandra left the meeting to get her things and agreed to come back shortly
- In the interim, the DIS attempted to find a clinic or case manager that could see her ASAP on a drop in basis, but given that it was past 4pm on a weekday it was not possible to identify a location or person to connect her with, so the focus was put on finding her shelter for the night. Past 5pm on a weekday all HIV care services in the area are closed.
- The DIS waited over three hours for Cassandra, who did not come back to the fast food restaurant until after 8pm.
- Cassandra was adamant that she did not want to go to the emergency room in the local area. Since her release from drug treatment, she had attempted to access HIV medical care at both of the hospital ERs in the area and reported negative experiences and feeling stigmatized and traumatized.
- Given the time of day there were limited options for shelter and they agreed to transport her to a different city with more shelter options so she could be safe for the night.
- At the shelter Cassandra was given a hot meal and the DIS provided instructions about where she could go in the morning for medical care services.
- The medical clinic was called in the morning to alert them that Cassandra would be coming in.
- The DIS was able to confirm she did not make it to the clinic the next day.

- After repeated attempts the DIS was able to reach Cassandra through her mother (who has regular phone calls with her) and set up a time to meet her to help her get to the clinic.
- Cassandra did not make the meeting time after three hours and the DIS had to leave.
- Cassandra showed up at the location a half hour later, per a phone call from her mom to the DIS.
- The DIS asked her mother to try to encourage her to go to the emergency room and advocate for herself.
- To date, Cassandra has not made it into medical care and the DIS is still trying to connect her to a low-threshold clinic and case management services.

## **Case study #2 – George and Fred**

- George and Fred are a couple who live in a rural county, about 30 minutes away from the nearest metropolitan area
- George is male, in his mid-20s, American Indian/Alaskan Native. He uses methamphetamine regularly and has a history of multiple STDs.
- Fred is also male and in his mid-20s. He is Native Hawaiian/Pacific Islander. Like George, he uses methamphetamine regularly and has a history of multiple STDs.
- They are both living with HIV
- They have generally lived in the rural town either with their families or couch surfing either in the local area or in Seattle.
- Given some of the history from DIS and health care providers, it is suspected that the couple is involved in drug runs between their rural residence and the nearest big city, as well as possible commercial sex work, party and play, or some combination of these circumstances.
- They have both had numerous reinfections of multiple STDs over the years.
- They have an open relationship, and their relationship itself has been on/off over the years.
- They both have been named by other cases for both STDs and HIV.
- George has never been located by DIS for interview or linkage to services after his original HIV diagnosis.
- Fred was located by DIS only when he was in jail and needed treatment for Gonorrhea.
- George was able to seek services at a satellite HIV clinic that is only open once a month, with Fred in the waiting room. The case manager attempted to work with Fred to seek services while he was there but he refused and walked out.
- Meth use has posed a constant challenge for both George and Fred being successfully linked to care.
- As of today, both patients seem to be successfully engaged in medical care for their HIV, both have current suppressed viral loads.
  - Despite being successfully engaged in care, both patients still have regular incidence of bacterial STDs, often with inadequate/improper treatment or testing from providers both locally and in the city they go to frequently.

## **Case Study #3**

Karen, a 17 year old Latina girl in one of the larger counties, was diagnosed with syphilis and chlamydia. A DIS attempted to contact her to provide partner services. She was eventually tracked down in juvenile detention.

When interviewed he named her boyfriend, Ned, and a woman she thought he was cheating on her with, Betty. DIS tracked down the boyfriend and learned he was diagnosed with HIV the year prior. He reported to the DIS identifying as bisexual. He was tested for syphilis and diagnosed. The DIS arranged for a public health nurse and case manager to come out with her in the field to do syphilis treatment and intake for HIV case management. Ned has not able to maintain care and to date is still out of care. The DIS found Betty through her social media account. On her account was a picture of her holding a baby and noting the date she had given birth to the baby. Given the date and details from the cases, the DIS was concerned that the baby have acquired congenital syphilis. The DIS found the baby when he was 4 months old in foster care – he only weighed 11 pounds and was very sick. The DIS worked with the pediatrician and CPS to get the baby tested for syphilis. The baby did have syphilis and was treated. Currently the baby is medically well.

#### **Case Study #4 – an administrative example**

Recently Carri Comer has pulled together a clinical advisory group to inform our work to address HIV medications on the Medicaid preferred drug list. There is some interest in continuing this group to advise us on other topics and issues. Concurrently, for Hep C Free WA there is a Clinical Strategies Work Group providing clinical recommendations and advice regarding our approach to HCV. Some of the same clinicians sit in both groups. As we move toward a more syndemic approach to our work and try to work more efficiently we are realizing situations like this may be opportunities to integrate our work. This is an example of an area administratively where we can address our work differently – to that end, we are considering a more integrated clinical advisory group to address HIV, STDs, and HCV.